



ARE ALL PEOPLE WITH A-T CONSIDERED TO BE AT HIGH RISK FROM COVID-19?

Especially because of their lung and neurological problems, all people with ataxia-telangiectasia (A-T) are considered to have a high-risk medical condition. They should receive a high priority and be immunized with the COVID-19 vaccine as soon as the rollout includes this category in their geographic area.

The guidance from the Centers for Disease Control about excluding people with immunodeficiency should not be applied to people with A-T. (The FDA restriction for immunocompromised people was set because the vaccine has not been tested in that group of people. In the case of A-T patients who have low immunoglobulin levels or T-cell number, however, there is no additional risk of harm from the vaccine. There is risk that the vaccine may not work and provide a false sense of security, but this risk can be addressed by measuring anti-COVID-19 antibody levels after immunization, as explained below.)

Whether caregivers and other household members can be vaccinated at the same time as the person with A-T will depend on state and local health department policies.

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WILL THE VACCINE BE EFFECTIVE IN PEOPLE WITH A-T?

The two COVID-19 vaccines that are currently available in the U.S. are proven to be about 95% effective in the general population. They may or may not be effective in a person with A-T, depending on the degree and type of immunodeficiency the person with A-T has. People with A-T should receive a COVID-19 vaccine whether or not they previously had a COVID-19 infection, and whether or not they are receiving gamma globulin therapy (such as IVIG or SCIG). Gamma globulin will not provide COVID-19 protection until after a substantial number of people have been vaccinated or infected with COVID-19 and have then donated their plasma to make gamma globulin. Gamma globulin with protective levels of antibody to COVID-19 will likely not be available for at least a year.

The COVID-19 vaccine is unlikely to provide protection to people with A-T who are undergoing chemotherapy or on a high dose of an immunosuppressing agent, such as prednisone. People in this category should talk to their doctor about getting the vaccine, but it will likely not provide protection. Note, however, that A-T patients currently participating in the Erydel-sponsored clinical trial of EryDex (dexamethasone) for A-T can still receive a COVID-19 vaccine, as the steroid dose given in that trial is too small to interfere with the vaccine.

Even after receiving the vaccine, one cannot assume that it has generated anti-COVID-19 antibodies and protected a person with A-T from COVID-19 infection. Therefore, a blood test for levels of the anti-COVID-19 antibody should be performed four to six weeks after the second dose of vaccine has been received.

- If the test for the anti-COVID-19 antibody shows a high level of antibody and the person does not have a history of underlying lung disease, they may feel a little more comfortable about resuming their activities in the community, as long as they and the people around them continue to wear masks, and practice careful handwashing and social distancing. Antibody levels should be re-checked in four to six months to see if protective levels of antibody are maintained.
- If the test for the anti-COVID-19 antibody shows a low level of antibody, the person with A-T should assume that they do not have protection and continue to maintain all current safety protocols.

In the general population, it's not clear how long the vaccine will prevent infection, but we should know this soon.

COVID-19 VACCINES AND ATAXIA-TELANGIECTASIA

CAN THE VACCINE CAUSE YOU TO BE INFECTED WITH COVID-19?

One cannot be infected by the COVID-19 virus from receiving any of the vaccines, as they do not contain the live virus.

WHICH COVID-19 VACCINE IS BEST?

There are two vaccines currently approved in the United States – the Pfizer and Moderna vaccines. They both use new messenger RNA (mRNA) technology and have a possible advantage over other types of vaccines. The two vaccines have similar efficacy in preventing symptomatic infection and have similar side-effect profiles. The Pfizer vaccine has been approved for use in people age 16 and older, and the Moderna vaccine has been approved for those age 18 and older. There are no vaccines currently approved for children under the age of 16, and it will likely be several months before we know more about this.

CAN PEOPLE WITH A-T HAVE AN ALLERGIC REACTION TO THE VACCINE?

If anyone has a history of an allergic reaction to any drug, they should consult their doctor or allergist before receiving the COVID-19 vaccine. That being said, the rare, sudden allergic reaction to the vaccine (anaphylaxis) seen in some people who do not have A-T should not be a risk for A-T patients, because the majority of people with A-T do not have the IgE antibody that causes this type of reaction.

DO A-T CARRIERS HAVE SPECIFIC RISKS WITH THE VACCINE?

Biological parents and some siblings of children with A-T are A-T carriers and carry one copy of the mutated ATM gene. There is no increased risk above that of the general population for carriers regarding COVID-19 or the COVID-19 vaccines. For any specific concerns about contraindications (i.e., reasons not to receive the vaccine, such as allergies, autoimmune problems, etc.), check with your local doctor.

WHAT SIDE EFFECTS CAN BE EXPECTED?

The possible side effects of the vaccines (fatigue, headache, soreness at the injection site, low-grade fever or flu-like symptoms) should be no more likely or more severe in people with A-T or A-T carriers than in the general population.

DO WE NEED TO MAINTAIN SAFETY PROTOCOLS AFTER WE ARE VACCINATED?

Right now, we know that vaccines decrease the chance of a severe infection or of showing symptoms at all. We do NOT know if people who have received the vaccine can still spread COVID-19. With that in mind, it is critical to continue wearing masks, carefully washing hands and maintaining social distancing even after receiving the vaccine.

Please note: This guidance is based on what is known about available COVID-19 vaccines in the United States as of January 18, 2021.



Ataxia-telangiectasia (A-T) is a genetic disease that causes loss of muscle control and balance, cancer, lung disease and immune system problems in children and young adults, shortening their lives. The nonprofit A-T Children's Project partners with academic and industry investigators worldwide – organizing and supporting innovative research, conferences, clinical teams, data platforms and biomarkers – to optimize disease management strategies, develop new treatments and find a cure.

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